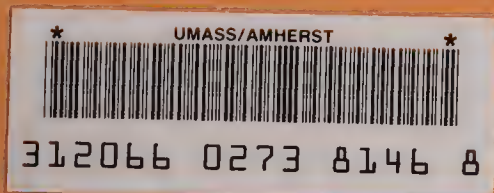


(MASS: ELI, 2: AL 98



EXECUTIVE OFFICE OF ELDER AFFAIRS



ALZHEIMERS DISEASE

Principles of Caregiving and Resources for Caregivers



MICHAEL S. DUKAKIS
GOVERNOR

Paul J. Lanzikos
SECRETARY

ROBERT L. MOLLIKA
ASSISTANT SECRETARY
FOR POLICY AND PLANNING

ROBERT CHAMBERS
DIRECTOR, ALZHEIMER'S
INFORMATION OFFICE

Dear Reader:

Alzheimer's Disease is the most prevalent and the most devastating, dementing illness of the aged. It is a little known but surprisingly common disorder that affects the cells of the brain. This disease has produced intellectual impairment in over 1.5 million American adults.

In August of 1984, the State Legislature passed legislation filed by the Executive Office of Elder Affairs creating the Governor's Special Commission on Alzheimer's Disease. Between November of 1984 and July of 1985, when a final report was presented to Governor Michael S. Dukakis and the Legislature, this committee held two public hearings and many subcommittee meetings. Since September of 1985, an office of Alzheimer's Information has existed within the Executive Office of Elder Affairs.

The purpose of this pamphlet is to assist family members and other caregivers to gain information as to the resources available to them. For further information please contact the Alzheimer's Information Office at (617) 727-4415 or toll-free at 1-800-351-2299.

Sincerely,

A handwritten signature in dark ink, appearing to read "Paul Lanzakos". The signature is fluid and cursive, with the first name "Paul" and last name "Lanzakos" clearly distinguishable.

Paul Lanzakos

INTRODUCTION

This pamphlet has been prepared for families and others who are caring for Alzheimer's patients at home. It responds to many questions that arise in the course of caring for an Alzheimer's patient, and it offers some concrete suggestions for daily management. An overriding theme is the importance of support from family, friends, and community resources for the primary caregiver. It is important to stress not only patient care, but self-care. The emotional, physical, financial, and social costs are enormous, and this pamphlet has been prepared to assist you in the care that you provide. For further information, call (617) 727-4415 or toll free 1-800-351-2299.

ACKNOWLEDGEMENT

A major contribution to this pamphlet was made by the Alzheimer's Resource Center of the New York City Department on Aging. Their manual is entitled "Caring - A Family Guide to Managing the Alzheimer's Patient at Home."

PRINCIPLES OF CAREGIVING AND RESOURCES FOR CAREGIVERS

Any long-term, disabling illness is difficult for the afflicted individual and for family members who are directly or indirectly involved in his/her care. Alzheimer's disease has a profound effect on almost all areas of the patient's and family's lives, interfering with work, social activities, plans for the future, and the activities of daily life that seemed routine, predictable, and enjoyable up to the time of diagnosis. The stress felt by caregivers can at times be overwhelming. Emotional support and assistance with caregiving -- from family, friends, and community resources -- are therefore essential for the optimal functioning of both patient and primary caregiver. Sometimes, help from a professional counselor is valuable.

Alzheimer's gradually robs the patient of the intellectual capacity, personality attributes and abilities that once made them who they were. Family members frequently feel cheated and angry about these changes and may feel they no longer recognize the individual who was once a source of support, sexual companionship, guidance, and insurance against the loneliness of old age. Alzheimer's disease has been described as a disease of separation which results in the loss of the patient in bits and pieces. It is difficult to prepare oneself emotionally for the time in the final stage of the disease when many patients are unable to recognize the spouse or child on whom they have been depending for years.

When patient and family receive a diagnosis, they learn that the disease is incurable and that the patient will become progressively more impaired.

The stress of caregiving is increased by knowing that most Alzheimer's patients may live with the disease for many years, eventually requiring constant supervision and twenty-four-hour-a-day care. Not only will the patient become totally dependent for assistance in such basic tasks as eating and dressing, but may also develop symptoms which are irritating and even frightening to family members.

Although there is no cure for the disease and no way to stop the progressive deterioration that characterizes its course, some things can be done to maintain the patient at an optimal level of functioning, and to make ones life as comfortable and enjoyable as possible. There are also ways to make caring for the patient easier on the family.

Principles of Caregiving

There are no right or wrong ways to care for an Alzheimer's patient, but experience has shown that following certain simple guidelines usually helps both patient and family. You may find the following guidelines, or "principles of caregiving," useful in caring for a relative diagnosed as having Alzheimer's disease:

- ° Inform yourself about Alzheimer's disease and about the services available to you and the patient. Knowing something about the disease -- particularly the typical course and symptoms -- will give you an idea of what to expect, lessen the surprises you'll have to deal with and help you to feel a bit more in control of what's happening. Information will also enable you to provide better care for the patient today and to plan more appropriately for the future.



Digitized by the Internet Archive
in 2013

<http://archive.org/details/alzheimersdisease00mass>

Families of Alzheimer's patients usually say that the best way to deal with the disease is to take one day at a time and not worry about what tomorrow will bring. While this is sound advice in many respects, caregivers also acknowledge the need to come to terms with the fact that the patient has an incurable disease with a predictable downward course. They will require an increasing amount of care and perhaps eventual institutionalization.

Knowing the future, you will want to give some thought to care arrangements compatible with the patient's needs and your resources. Informing yourself about available options -- including nursing home care -- doesn't require that you make early decisions about the patient's future. The best time for planning is in the initial stage of the disease process, before you are forced to take action. Soon after the diagnosis is made is also the time to investigate the legal and financial issues raised by a long-term and incapacitating disease like Alzheimer's. If you can locate an attorney knowledgeable about the special problems facing Alzheimer's patients and their families, consulting such a specialist is prudent. The goal of legal and financial planning is to ensure your ability to provide the patient with needed care, while at the same time planning for your own future.

- ° If you do not already have one, find a doctor who has experience treating Alzheimer's patients and who can help you and the patient throughout the course of the disease. This doctor might be the physician who diagnosed your relative or another physician. The patient should have ongoing medical supervision, as even minor, superimposed

illnesses may aggravate his Alzheimer's symptoms. Many patients have co-existing conditions like diabetes and high blood pressure, which must be monitored; and medications may be needed for these conditions or for the management of Alzheimer's symptoms. Because patients gradually lose the ability to communicate exactly how they feel, the doctor you select must have sufficient patience and experience to determine whether an additional medical problem exists and how best to treat it.

- ° Try to make life now as similar as possible to the way it's always been. Allow and encourage the patient to do as much for himself as he can -- for as long as possible. Try not to jump in and do something for the patient just because it's taking him a long time or he is having difficulty. On the other hand, don't hold back assistance until frustration reaches unmanageable levels.

Give the patient just enough assistance to accomplish the task at hand, and simplify tasks as needed so that the patient can do them using remaining abilities. "Just enough assistance" may be a simple, verbal reminder of what to do or step-by-step instructions. Demonstrating a task may work better than describing it for more impaired patients, and some will need the caregiver to physically guide their movements. The amount and type of assistance a patient needs will vary from task to task and from one day to the next. Doing a task the same way each time tends to make it easier for the patient.

- ° Modify the patient's surroundings as needed, making it easier for him to function with safety and independence. You can use the environmental checklist found at the end of this pamphlet to insure that the home is safe, simple, and consistent enough for an Alzheimer's patient.

- ° Establish a simple and predictable routine for the patient as his need for structure increases. The patient's routine should vary as little as possible from day to day.

To assist the patient, describe the routine in a written schedule of daily activities. Write the day and date at the top of the schedule and list all planned activities and the times they will occur. Review the schedule with the patient each morning.

- ° Be mindful of the patient's increasing need for structure, consistency, and direction in all activities. Repeat information and instructions frequently and try to be supportive and reassuring.

The patient will also need more and more help understanding the world around him. He may lose his sense of time and become confused about where he is and who the people around him are. The things he sees, hears and experience may make little sense to him without interpretation. Reality orientation -- the process of providing clues and reminders which help ground the patient in reality -- is advocated by most experts on Alzheimer's disease. The schedule of daily activities described above is a reality orientation device.

- ° Simplify the way you talk to the patient as his ability to understand and use language diminishes. You may find the communication disorders caused by Alzheimer's disease less frustrating if you modify your communication goals as the patient loses language skills. In the middle to late stages of the disease, for example, your primary goal might be to communicate just enough to meet the patient's most basic needs for

affection and physical care. Much of the communication might be nonverbal.

Consult your doctor if you notice a dramatic change in the patient's mood or behavior, such as sudden or extreme agitation or lethargy. Behavior changes may be symptomatic of physical or psychiatric illness. Don't be afraid to "bother the doctor" -- he is there to advise you and to help the patient. Any suicidal attempts should be reported immediately.

- ° Don't neglect yourself. It is as important for you as it is for the patient to eat properly and to get enough sleep and exercise. Spending time alone or with friends and family may be a welcome change from patient care. Many caregivers focus total attention on the patient, whose needs they feel have become "more important" than their own. The patient is not the only legitimate recipient of support, understanding, and encouragement. Your needs do not stop when a loved one become ill with Alzheimer's disease.
- ° Get help with caregiving and seek out respite, or time away from the patient. Contact your local Home Care Corporation which provides respite care and other services. Enroll the patient in an adult day care program, hire a home care aide, or ask a friend or family member to spend a few hours with the patient, if possible. How you spend your time away is up to you --you may join an Alzheimer's family support group, go to a movie, take an exercise class, go for a walk, or visit a friend. An Alzheimer's patient does not need you with him every moment -- a sensitive, caring replacement will usually be just fine for a few hours a day.

Many caregivers are reluctant to ask for help from family, friends, and professionals. A mother may not want to burden her adult children, who may have families of their own or may be uncomfortable with their father's decline. Friends may be disappointing in their inability to cope with the patient's emotional or cognitive changes or with his strange behavior. Some friends will avoid you and the patient, and others may reach out in ways you never expected. The ability to accept and use offers of help will not only relieve the physical and emotional burdens of caregiving, but will also give you opportunities to maintain ties with people who are important to you.

Help "surrogate caregivers" manage the patient successfully by explaining what they can expect and how to handle problems which arise. Remember that no one else may know the patient as well as you do or understand how Alzheimer's disease has affected him. Furthermore, you may have learned, through trial and error, management techniques which a stranger might not even think to try.

- ° Consider meeting with a counselor or psychotherapist if you feel anxious or depressed. Short-term psychotherapy may help you to function better in your role, to understand the patient and to accept feelings, such as anger, fear, and helplessness, you may now consider unacceptable. Denying how you feel (whether to "protect the patient," to "put up a good front" for family and friends or because you "do not have the time or energy" to think about yourself) only makes matters worse. You are not "crazy" if you seek the help of a professional. In fact, getting help for yourself may give you more energy to cope with the task of caregiving.

As mentioned earlier, the entire family is affected by a diagnosis of Alzheimer's disease. Stress of this kind may stimulate old battles or lead to new misunderstandings. This is not a time for emotional strain and isolation among family members. Counseling for the whole family may relieve tensions, and help the family to function as a team. Convincing reluctant family members to get help is not easy -- but it is worth a try.

Handling Disturbing Behavior

Caregivers often ask how to handle the disturbing behavior which can be caused by Alzheimer's disease. Psychiatric symptoms, such as delusions, hallucinations, depression or angry outbursts, tend to be the most upsetting to families. Other common behaviors, such as wandering, agitation, hiding, and hoarding things or inappropriate table manners, may be less frightening but no less confusing. Strange behaviors can embarrass, irritate or sadden family members who sometimes can't believe what they are seeing.

The following points may give you some ideas about how to respond to disturbing symptoms:

- ° First, try to understand if there is a precipitant. For example, was there a change in environment, routine, medication, or caregiver? Were you feeling rushed, less patient, angry at your impaired relative or at someone else? Was the weather rainy, preventing an outdoor excursion that was normally the highlight of the patient's day? Were there strange or unfamiliar noises or shadows that might have been misinterpreted by the patient because of his impaired capacity to understand what is seen and heard?

- ° The time of day may affect behavior. Many patients have been found to increase their wandering, pacing, agitation, or depressed mood in the late afternoon or early evening. This is known as the "sundown" effect. Although there may be little you can do to change or control this behavior, being able to anticipate its occurrence may help you to better plan activities.
- ° Certain behaviors may reflect the patient's attempt to cope with stress or tension. For example, fidgeting, rocking, pacing back and forth, or wandering may help to release energy that was once discharged in more goal-directed activities. If the patient is agitated, moving about may help him to feel better.
- ° Depression may appear in the early stages of the disease and create changes in eating, sleeping, and other behaviors. It is not surprising that someone who is aware of changes in his memory and other functioning may become depressed and frightened. False reassuring seldom works. Some patients may gain relief by talking to a professional counselor or psychotherapist to discuss fears about the future, regrets about the past and plans for the remaining years.
- ° Feelings of anxiety often explain the onset of certain behaviors such as wandering or hiding objects. Wandering may represent a search for security. Questions and statements such as "Where is my mother?" or "I want to go home" illustrate feelings of insecurity and fear. Reassurance at these times may be helpful. Saying things such as "I am here to take care of you," or "I know you are feeling frightened and alone," may calm and reassure an anxious patient.

- ° Paranoia, or suspiciousness, is a common symptom. Everything is less understandable, less manageable and more frightening to the patient. Some patients can be reassured by your efforts to understand how frightened and out of control they feel. Others may not respond as well, and may need medication if agitation becomes unmanageable.
- ° Too much stimulation, such as exposure to crowds, loud noise, unfamiliar places or events, may cause agitation or withdrawal. Restraining an agitated patient usually makes matters worse, increasing his fear and complicating your understanding of the causes. Medication should be used as a last resort to control behavior. It should always be given under the careful supervision of a physician, since adverse reactions can add to problems in patient functioning and management. Behavior modification issues are frequently discussed by family support groups.
- ° Chart when behaviors occur. This may help you to understand when, why and how behaviors and symptoms develop. Continue to use whatever interventions work, and discard those that don't for the time being. It is very important to remember that the patient's behavior will be unpredictable and that what worked last week, or even yesterday, may not be effective today. Equally important, remember that the patient's behavior is symptomatic of his illness; he is not intentionally doing things to annoy, anger or frighten you. Patience, flexibility, and good humor will make life easier for both you and the patient.

Services Available To The Patient and Family

The importance of taking advantage of all help available to you and the patient has been discussed. The following pages contain a table summarizing the major services available.

SUMMARY OF MAJOR SERVICES AVAILABLE TO
ALZHEIMER'S VICTIMS AND THEIR FAMILIES

<u>Service</u>	<u>Description</u>
Information and Referral	A variety of organizations may be able to provide information on Alzheimer's Disease and refer you to the services described below. The Executive Office of Elder Affairs maintains a toll free hotline (1-800-351-2299) which provides information on services available to Alzheimer's victims and their caregivers. Another valuable source of information on available services would be the local Area Agency on Aging; a list of which is in the rear of this pamphlet. The local chapter of the Alzheimer's Disease and Related Disorders Association will provide information on family support groups and other resources (617-574-9394). Senior centers and Councils on Aging personnel will be knowledgeable about community services and public benefit programs. Discharge Planners and Social Service personnel at local hospitals may also be of assistance.
Home Care Corporations Area Agencies on Aging	In addition to the traditional services such as homemaker, personal care, chore, transportation, home delivered meals, etc., Home Care Corporations/Area Agencies on Aging now provide respite care services to enable caregivers to have some time to themselves. Respite care may be provided by supplying a companion, homemaker - personal care, social day care, adult day health, and even short term institutionalization. Further information can be obtained from the local Home Care Corporation/Area Agency on Aging.
Legal and Financial Advice	A diagnosis of Alzheimer's Disease raises a host of legal and financial issues which should be dealt with early in the illness. Many attorneys are beginning to specialize in the legal issues confronting elderly people. Additionally, all Area Agencies on Aging are mandated to sponsor cost free legal services programs for elders. In order to contact the legal service program in your area, please call your local Home Care Corporation/Area Agency on Aging.
Adult Day Care	Adult day care offers a safe and familiar environment and a structured program of activities for the patient. It also provides relief from caregiving for the family. Although the design of

adult day care programs varies, participants ordinarily attend for several hours a day, up to five days a week. A recent survey indicated that many Adult Day Health Programs in Massachusetts accept Alzheimer's victims. Finally, a small but growing number of adult day care programs are being established specifically for persons with Alzheimer's Disease and related disorders. Further information can be obtained from the Executive Office of Elder Affairs' Alzheimer's hotline (1-800-351-2299) or your local Area Agency on Aging.

Social Day Care Service

Social Day Care Service provides an individualized program of social activity for elders who require daytime supervision because of physical impairment or social or emotional problems that impair their capacity for self-care. Activities of Social Day Care include: assistance with walking; assistance with mealtime activities; assistance with grooming; nutrition services including a minimum of one (1) meal per day which is of suitable quality and quantity and supplies at least one-third (1/3) of the daily nutritional requirements; special diets must be made available if indicated by a client's Home Care Service plan; morning and afternoon snacks should be available for clients at the day care center; and client activities, including planned recreational and social activities suited to the needs of participants and designed to encourage physical and mental exercise and stimulate social interaction. Social Day Care Services must be provided by trained and supervised staff.

Family Support Groups

Family support groups are composed of the friends and relatives of Alzheimer's patients who meet regularly to share information and discuss common problems. They are a good source of information about the disease and about resources available to patients and their families. They also offer caregivers a chance to give and receive encouragement, support, and understanding from others coping with similar difficulties.

ADRDA has been very active in helping to organize family support groups. Others have been started by social service agencies, adult day care programs and the medical centers which perform diagnostic evaluations.

Individual or Family Counseling

Counseling is provided by private practitioners, and

in some instances, by community mental health centers. It is recommended for caregivers who find that the emotional support from family and friends is simply not enough. The Executive Office of Elder Affairs maintains a list of community mental health centers in the Commonwealth.
(1-800-351-2299)

Nursing Homes

Many families are eventually unable to care for relatives with Alzheimer's Disease at home, even if extensive support is available. Although nursing home placement is usually the choice of last resort, it often becomes the most appropriate and responsible care option for patients in the later stages of the disease. At this point, the care the patient requires may be more demanding and skilled than the family can provide.

Even if the victim is to pay for nursing home care privately, families are strongly encouraged to contact the Long Term Care Connection Program of the Medicaid Division of the Department of Public Welfare. For assistance in finding the appropriate office, please call 1-800-351-2299. Another resource in finding a nursing home bed is the Long Term Care Ombudsman Program which is funded by the local Area Agency on Aging. For information on the quality of care provided by a given nursing home, call or write the Division of Health Care Quality, Department of Public Health, 150 Tremont Street, Boston, MA 02111. The "Surveyor of the Day" can be reached at (617) 727-5860 or toll free at 1-800-462-5531.

TYPICAL SYMPTOMS OF EARLY, MIDDLE, AND LATE STAGES
OF ALZHEIMER'S DISEASE

<u>Ability/Sphere Affected</u>	<u>Early Alzheimer's</u>	<u>Middle Alzheimer's</u>	<u>Late Alzheimer's</u>
<u>Memory</u>	Has trouble remembering recent events; may have difficulty remembering names, finding the right word, and remembering thoughts; misplaces familiar items like keys or glasses; may have difficulty relaying phone messages; may forget appointments; may get lost during a trip to a familiar place	Is largely unaware of all recent events and experiences; can still remember more distant past; cannot form new memories and cannot learn	Has no apparent or recent remote memory
<u>Cognitive Ability</u>	Has difficulty handling finances (e.g. paying bills, balancing a check-book, making change); has difficulty performing complex but familiar tasks like playing bridge; may have difficulty telling time; may no longer be capable of working	Has great difficulty making decisions and choices; is unable to do even simple arithmetic calculations; has difficulty concentrating and easily loses thread of a story; needs to be instructed about how to complete tasks (tasks must be broken down into steps and instructions repeated frequently); shows poor judgement; loses sense of time and place and often forgets where he is and what time, day, and season it is.	Has little observable cognitive function
<u>Coordination/Motor Skills</u>	Still has generally good coordination and motor skills; may have slowed reaction time and may be unable to drive	Loses coordination and balance; may have difficulty making body do what mind wants it to do; may be unsteady, bump into things and fall easily; may have	Usually loses ability to walk and sit up; may lose ability to swallow; may go into a stupor or coma

<u>Ability/Sphere Affected</u>	<u>Early Alzheimer's</u>	<u>Middle Alzheimer's</u>	<u>Late Alzheimer's</u>
<u>Mood and Behavior</u>	Experiences mood swings, socially withdrawn, easily distracted; seeks out and prefers the familiar; is less spontaneous; shows less initiative; may deny forgetfulness and confusion; may suffer from depression	difficulty walking; loses ability to write legibly Experiences frequent mood swings; is increasingly self-absorbed and insensitive to feelings of others; shows little warmth; may become agitated, pace, wander, become suspicious, suffer from delusions or hallucinations; may suffer from sleep disturbances like not sleeping through the night	Is often agitated; usually seems oblivious to environment and to others; may not recognize primary caregiver
<u>Ability to Carry Out Activities of Daily Living</u>	Carries out activities of daily living with little or no assistance	Needs assistance with activities of daily living; may have trouble choosing appropriate clothing for season and occasion and may have difficulty putting the clothing on properly; may develop fear of bathing or have trouble with the mechanics of bathing; may forget where the bathroom is and have difficulty with mechanics of toileting; may develop incontinence of urine followed by incontinence of feces	Needs extensive assistance with most basic activities of daily living or requires total care (e.g. must be bathed, dressed, groomed.)
<u>Language</u>	May desire to communicate less, but speech is generally unaffected; has slightly reduced vocabulary; has difficulty	Talks less or may repeat words or phrases continuously; has slower speech filled with pauses and in-	May lose ability to speak altogether or vocabulary may be limit to one or two words; may be

Ability/Sphere
Affected

Early
Alzheimer's

Middle
Alzheimer's

Late
Alzheimer's

with word finding; is
vague; may occasionally
say irrelevant things

terrutions; uses
complete sentences
infrequently and
frequently revises
what has been said;
may make little sense
and has difficulty
constructing
sentences; has a
significantly reduced
vocabulary; may lose
the ability to under-
stand written and/or
spoken language;
may invent words;
must have instruc-
tions repeated

able to repeat
words or simple
phrases without
understanding
meaning; may
repeat remaining
word(s) continuously
may be unable to
understand what is
being said

ENVIRONMENTAL CHECKLIST

Take this checklist with you as you walk through every room in your home. Indicate with a check if the answer to each question is yes.

Throughout the Home

- ° Has the house or apartment been cleared of clutter and simplified as much as possible? [What you want to create is an environment which has what the Alzheimer's patient needs in it but as few other objects as possible.] _____
- ° Are furnishings and often-used items always kept in the same place? _____
- ° Is constant noise and confusion avoided? Are the television and radio shut off when not in use? [An Alzheimer's patient generally does better in quiet, calm environment, although soft, classical music may be calming]. _____
- ° Are electric and extension cords in good condition and secured in a way which minimizes the possibility of someone tripping over them? _____
- ° Is the house or apartment well lit? Are shiny floors with busy patterns avoided? [If the patient bumps into walls or furniture despite good lighting, placing reflector tape on furniture corners or along baseboards may help]. _____
- ° Are there working night lights in the hallways? Are they turned on at night? _____
- ° Do all stairways have banisters? Are they well secured? _____
- ° Are stairs and hallways free from clutter which could cause a fall? _____
- ° Is the top of each stairway protected with a safety gate to prevent falls? [Such gates may only be needed at night]. _____
- ° Is there adequate space for the patient to pace and otherwise move freely? [Many Alzheimer's patients become agitated and need space to move around.] _____
- ° Have all tools and appliances the patient can no longer use safely been removed or locked up? [Such tools and appliances may include an iron, hairdryer, razor, electric mixer or food processor, sewing machine, lawn mower, electric knife, heating pad, and power tools]. _____

- Have all firearms been locked up? _____
- Are the car keys kept in a place where the patient can't find them? _____
- Have all paints, solvents, insecticides, and poisons been locked up? _____
- Are all doors secured in such a way that the patient can't get out without assistance? [Wandering is a common symptom of Alzheimer's Disease and can be extremely dangerous if the patient becomes lost or disoriented outside. Locks can help prevent wandering but must be installed in such a way to make the patient's "escape" difficult without making access to the house impossible in the event of an emergency like a fire. Because Alzheimer's Disease makes the acquisition of new knowledge difficult or impossible, installing a new and unfamiliar lock or placing an old lock in a different place on the door may be enough to prevent the patient from opening the door.] _____
- Are all windows secured in such a way that the patient can't get out without assistance? [It is essential that the windows be easily opened in the event of a fire. If you have any questions about the safest way to secure your windows, consult the Fire Department]. _____
- Have all radiators been blocked off or covered with radiator guards? What about exposed hot water pipes? _____
- Is the use of cigarettes and matches either prohibited or carefully supervised? [Cigarettes and matches handled by an intellectually impaired person are a major fire hazard]. _____
- Have interior doors been altered to prevent the patient from accidentally locking himself in a room? [This can be done by removing the locks or taping the door latch open]. _____

Kitchen

- Is the stove inoperable when not in use? [Improperly operated stoves are a major cause of accidental injury and fire. For the safest and most effective way to make the stove inoperable, consult the dealer, your repairmen, the gas company, or an electrician]. _____
- Have all cleaning products, polishes, bleaches, and detergents been removed or locked up? _____

Patient's Bedroom

- Has everything the patient doesn't need and use regularly been removed from the room to make it as simple and uncluttered as possible? [Remember to go through all closets and drawers, removing everything except the clothes the patient uses on a day-to-day basis]. _____
- Is there a sturdy lamp by the patient's bed which he can operate easily without knocking it over? [A remote control on/off switch with a simple push button control may be helpful]. _____
- Have all area rugs been removed from around the patient's bed? [These are easy to slip on, particularly when getting out of bed at night or when in a hurry]. _____
- Is there a clear and unobstructed path between the patient's bed and the bathroom? _____
- Is the patient's room well lit? _____
- Is there a working night light in the patient's room? Is it turned on at night? _____

Patient's Bathroom

- Has everything been removed from the bathroom except such essentials as a towel, a bar of soap, a toothbrush, and some toothpaste? [It is best to keep the bathroom as simple as possible and to provide the patient with shampoo, an extra towel, the denture case, the shaving cream, etc. only when needed. As the disease progresses, even the towel, soap, toothbrush, and toothpaste may be used inappropriately if left out]. _____
- Have all medications (both over the counter and prescription) and toiletries been removed from the bathroom? [Remember to clear out or lock up the medicine cabinet. You should dispense all medications]. _____
- Are there non-slip decals or a non-skid mat in the tub or shower? [To avoid confusing the patient, it is best to use mats and decals which blend in with the color of the tub or shower]. _____
- Are there grab bars in the tub and shower for the patient to hold onto while getting into the tub and while taking a bath or shower? [The mere presence of grab bars does not guarantee safety. Make sure that they are bolted to the wall and that they are installed at a height and in a location convenient for the patient to use]. _____
- If the patient has difficulty using the bathtub, is the bathroom equipped with a bathtub bench and a hand-held shower? _____

- ° If the patient has difficulty using the toilet because of stiffness or unsteadiness, is the bathroom equipped with grab bars around the toilet and with an elevated toilet seat available through most medical supply houses? _____
- ° If the bathroom is far from the patient's bedroom, is a portable commode kept in the bedroom? _____
- ° Are small rugs and bathmats removed except when the patient is getting out of the tub or shower? Do the rugs or mats have non-skid bottoms? [Such rugs and bathmats should be used only to keep the patient from getting the floor wet and making it slippery]. _____
- ° Does the bathroom have a working night light? Is it turned on at night? _____

Although not directly related to the home environment, there are a number of additional safety precautions a family caring for an Alzheimer's patient should take. For example, the family should have a written emergency plan describing procedures to be followed in the event of a medical emergency, a fire, or the patient's wandering away from home. The plan should be posted near the telephone, along with telephone numbers of the Police and Fire Departments, the local poison control center, and the family doctor. Notify the local police precinct immediately if the patient wanders away.

Keep a recent photograph of your relative on hand, as well as photocopies which can be quickly distributed to the police and to neighbors if the patient get out unaccompanied. Obtain an identification bracelet for the patient which gives his name and address and indicates that he is memory-impaired.

It may be wise to inform your neighbors that your relative has Alzheimer's Disease, particularly if he has a tendency to wander. Informing them of the nature of his illness, and telling them what to do if he is seen outside alone, may help prevent his wandering beyond the neighborhood. There are innumerable stories of disoriented Alzheimer's patients being returned home by caring neighbors and local merchants.

A final safety precaution involves the decision about whether to leave your relative alone at home. You will have to use your judgement about whether he is intellectually intact enough to be left alone for even short periods of time. A patient whose behavior makes him a potential danger to himself or to others -- or a patient who can neither recognize nor respond appropriately to an emergency situation -- should not be left unsupervised.

Responding to an emergency situation frequently requires that a person be capable of communicating the need for help to others. One reason why an Alzheimer's patient may be incapable of responding is that he can no longer communicate that need clearly. The ability to both understand and use language diminishes as Alzheimer's Disease progresses.

AREA AGENCIES/HOME CARE CORPORATIONS BY REGION

Elder Home Care Services of
Worcester Area, Inc.
1241 Main Street
Worcester, MA 01603
(617) 756-1545

Auburn, Barre, Boylston, Grafton,
Hardwick, Holden, Leicester, Millbury,
New Braintree, Oakham, Paxton, Rutland,
Shrewsbury, West Boylston, and Worcester.

=====

* Chelsea/Revere/Winthrop
Elder Services
385 Broadway, Box 189
Revere, MA 02151
(617) 286-0550

Chelsea, Revere, and Winthrop.

=====

Central Boston Elder
Services, Inc.
1255 Boylston Street
Boston, MA 02115
(617) 266-1672

Allston, Back Bay, Brighton, Fenway,
Jamaica Plain, North Dorchester, Parker Hill,
Roxbury, and South End.

=====

* Elder Services of Cape Cod
and the Islands, Inc.
68 Route 134
South Dennis, MA 02660
(617) 394-4630 or
1-800-352-7178

Barnstable, Bourne, Brewster, Chatham,
Chilmark, Dennis, Eastham, Edgartown,
Falmouth, Gay Head, Harwich, Mashpee,
Nantucket, Oak Bluffs, Orleans, Provincetown,
Sandwich, Tisbury, Truro, Wellfleet, West
Tisbury, and Yarmouth.

=====

* Elder Services of Berkshire
County, Inc.
100 North Street
Pittsfield, MA 01201
(413) 499-1353

Adams, Alford, Becket, Cheshire, Clarksburg,
Dalton, Egremont, Florida, Great Barrington,
Hancock, Hinsdale, Lanesborough, Lee, Lenox,
Monterey, Mount Washington, New Ashford,
New Marlborough, North Adams, Otis, Peru,
Pittsfield, Richmond, Sandisfield, Savoy,
Sheffield, Stockbridge, Tyringham, Washington,
West Stockbridge, Williamstown, and Windsor.

=====

* Bristol County Home Care
for Elderly, Inc.
182 North Main Street
Fall, River, MA 02720
(617) 675-2101

Attleboro, Berkley, Dighton, Fall River,
Freetown, Mansfield, North Attleboro, Norton,
Raynham, Rehoboth, Seekonk, Somerset,
Swansea, Taunton, and Westport.

=====

* Franklin County Home Care
Corporation
Central Street
Turner Falls, MA 01376
(413) 774-2994

Ashfield, Athol, Bernardston, Buckland,
Charlemont, Colrain, Conway, Deerfield,
Erving, Gill, Greenfield, Hawley, Heath,
Leverett, Leyden, Monroe, Montague, New Salem,
Northfield, Organge, Petersham, Phillipston,
Rowe, Royalston, Shelburne, Shutesbury,
Sunderland, Warwick, Wendell, and Whately.

=====

<p>* Greater Lynn Senior Services 90 Exchange Street Lynn, MA 01901 (617) 599-0110</p>	<p>Lynn, Lynnfield, Nahant, Saugus, and Swampscott.</p>
=====	
<p>* Greater Springfield Senior Services, Inc. 661 Industry Avenue Springfield, MA 01104 (413) 781-8800</p>	<p>Agawam, Brimfield, East Longmeadow, Hampden, Holland, Longmeadow, Monson, Palmer, Springfield, Wales, West Springfield, and Wilbraham.</p>
=====	
<p>* Highland Valley Elder Service Center, Inc. 320 Riverside Drive Northampton, MA 01060 (413) 586-2000 or 1-800-322-0551</p>	<p>Amherst, Blandford, Chester, Chesterfield, Cummington, Easthampton, Goshen, Granville, Hadley, Hatfield, Huntington, Middlefield, Montgomery, Northampton, Pelham, Plainfield, Russell, Southampton, Southwick, Tolland, Westfield, Westhampton, Williamsburg, and Worthington.</p>
=====	
<p>* King Philip Elder Services IGO Building Carpenter Street Foxboro, MA 02035 (617) 769-7440 543-2611</p>	<p>Canton, Dedham, Foxborough, Medfield, Millis, Norfolk, Norwood, Plainville, Sharon, Walpole, Westwood, and Wrentham.</p>
=====	
<p>Health and Social Services Consortium c/o Walpole Area VNA, Inc. P.O. Box 252 Walpole, MA 02081 (617) 668-1066</p>	<p>Canton, Dedham, Foxborough, Medfield, Millis, Norfolk, Norwood, Plainville, Sharon, Walpole, Westwood, and Wrentham.</p>
=====	
<p>Senior Home Care Services, Boston III, Inc. 38 Chauncy Street (4th floor) Boston, MA 02112 (617) 451-6400</p>	<p>Beacon Hill/West End, Charlestown, Chinatown, Columbia Point, Dorchester, East Boston, East Mattapan, North End, and South Boston.</p>
=====	
<p>* Elder Services of Merrimack Valley, Inc. 420 Common Street Lawrence, MA 01840 (617) 683-7747 or 1-800-892-0890</p>	<p>Amesbury, Andover, Billerica, Boxford, Chelmsford, Dracut, Dunstable, Georgetown, Groveland, Haverhill, Lawrence, Lowell, Merrimack, Methuen, Newbury, Newburyport, North Andover, Rowley, Salisbury, Tewksbury, Tyngsborough, Westford, and West Newbury.</p>
=====	
<p>* Minuteman Home Care 83 Hartwell Avenue Lexington, MA 02173 (617) 862-6200 or 263-8720</p>	<p>Acton, Arlington, Bedford, Boxborough, Burlington, Carlisle, Concord, Harvard, Lexington, Lincoln, Littleton, Maynard, Stow, Wilmington, Winchester, and Woburn.</p>
=====	

Montachusett Home Care Corporation 545 Westminster Street Fitchburg, MA 01420 (617) 345-7312	Ashburnham, Ashby, Ayer, Berlin, Bolton, Clinton, Fitchburg, Gardner, Groton, Hubbardston, Lancaster, Leominster, Lunenburg, Pepperell, Princeton, Shirley, Sterling, Templeton, Townsend, Westminster, and Winchendon.
=====	
* Mystic Valley Elder Services 661 Main St., Suite 110 Malden, MA 02148 (617) 324-7705	Everett, Malden, Medford, Melrose, North Reading, Reading, Stoneham, and Wakefield.
=====	
* North Shore Elder Services 484 Lowell Street Peabody, MA 01960 (617) 535-6220	Danvers, Marblehead, Middleton, Peabody, and Salem.
=====	
Old Colony Elderly Services 231 Main Street Brockton, MA 02401 (617) 584-1561, 584-4317, 586-3700 or 3001	Abington, Avon, Bridgewater, Brockton, Carver, Duxbury, East Bridgewater, Easton, Halifax, Hanover, Hanson, Kingston, Lakeville, Marshfield, Middleborough, Pembroke, Plymouth, Plympton, Rockland, Stoughton, Wareham, West Bridgewater, and Whitham.
=====	
* Old Colony Planning Council 9 Belmont Street Brockton, MA 02401 (617) 583-1833	(See Above)
=====	
* Senior Home Care Services, Inc. 2 Main Street Gloucester, MA 01930 (617) 281-1750	Beverly, Essex, Gloucester, Hamilton, Ipswich, Manchester, Rockport, Topsfield, and Wenhâam.
=====	
* Somerville/Cambridge Home Care One Davis Square Somerville, MA 02144 (617) 628-2601, 02	Cambridge and Somerville.
=====	
* Baypath Senior Citizens Services, nc. P.O. Box 2625 Framingham, MA 01701 (617) 620-0840	Ashland, Dover, Framingham, Holliston, Hopkinton, Hudson, Marlborough, Natick, Northborough, Sherborn, Southborough, Sudbury, Wayland, and Westborough.
=====	
* South Shore Elder Services 639 Granite Street Braintree, MA 02184 (617) 749-6832 or 383-9790	Braintree, Cohasset, Hingham, Holbrook, Hull, Milton, Norwell, Quincy, Randolph, Scituate, and Weymouth.
=====	

Southwest Boston Senior
Services
One Belgrade Avenue
Roslindale, MA 02131
(617) 325-6565; 66

Hyde Park, So. Jamaica Plain, Roslindale,
West Roxbury, and West Mattapan.

Tri-Valley Elder Services
284 Worcester Street
Southbridge, MA 01550
(617) 764-2501

Bellingham, Blackstone, Brookfield, Charlton,
Douglas, Dudley, East Brookfield, Franklin,
Hopedale, Medway, Mendon, Milford, Milville,
Northbridge, North Brookfield, Oxford,
Southbridge, Spencer, Sturbridge, Sutton,
Upton, Uxbridge, Warren, Webster, and
West Brookfield.

* Holyoke/Chicopee Regional
Senior Services, Corp.
198 High Street
Holyoke, MA 01040
(413) 538-9020

Belchertown, Chicopee, Granby, Holyoke,
Ludlow, South Hadley, and Ware.

* West Suburban Elder Services
Parker Office Building
124 Watertown Street
Watertown, MA 02172
(617) 969-0170

Belmont, Brookline, Needham, Newton, Waltham,
Watertown, Wellesley, and Weston.

* Coastline Elderly Services,
Inc.
106 Huttleston Avenue
Fairhaven, MA 02179
(617) 999-6400

Acushnet, Dartmouth, Fairhaven, Gosnold,
Marion, Mattapoisett, New Bedford, and
Rochester

* Commission on Affairs of the
Elderly
One City Hall Square
Boston, MA 02201
(617) 725-4366 or
722-4646 (Hotline)

* Region II Area Agency on Aging,
Inc.
1128 Main Street
Holden, MA 01520
(617) 829-5364
1-800-322-3032

* Area Agencies on Aging

